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“FILE ON 4”

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SISTER: And on the phone call that was just sent to a message bank at the police in Hull, she just said, ‘Just tell Mother everything’s going to be all right.’

SPILLER: Alison Davies made a last call to her mother. Shortly after this, Alison and her disabled son, Ryan, jumped to their deaths from the Humber Bridge. Her sisters still struggle to come to terms with their loss.

SISTER: In the back of her mind she was still thinking about others. She’d made up, she’d come to this momentous decision that life would be better for them both away from all the stresses and pressures and pain, and then the phone was switched off for the last time.

SPILLER: On File on 4, we investigate help for families caring for disabled children and claims of a growing crisis in respite care - breaks for families who look after children and adults with disabilities. We hear how a black hole in local authority budgets means parents might be denied support in the future. And we reveal new evidence about the effects of the Health Service funding crisis - and how cash cuts could hit some of Britain’s most vulnerable people.

## SIGNATURE TUNE

## ACTUALITY IN MARPLE

WOMAN: This is where Alison lived. You can see the butterfly in the doorway. It was what was on her coffin. It's beautiful, isn't it?

SPILLER: On an estate in Marple, near Stockport, neighbours remember Alison Davies and her twelve year old son Ryan.

WOMAN: That's where I live. So you can see I was really close, I could see Ryan going to school in a morning, the bus coming for him between ...

SISTER: Come and look at these pictures of Aunty Alison, and come and sit down, Amy. Look, that's the day that I took her to a medical presentation. See her there?

SPILLER: Ryan's cousins say he loved football and jokes.

COUSIN: We asked him, what was Ryan's favourite fish, and he said ...

SISTER: Go on, Adam, say it.

COUSIN: Fish and chips!

SISTER: And that was just typical Ryan, wasn't it?

COUSIN: Yes.

SISTER: You were saying about sharks and dolphins and he said his favourite fish was fish and chips.

COUSIN: Yes.

SISTER: He made us laugh, didn't he?

SPILLER: But Ryan had a condition called Fragile X, a genetic disorder. His disability meant he had serious learning difficulties. Ryan's dad had left the family whilst Ryan was still young. As he grew older his mum, Alison, cared for a child who had no sense of danger, was hyperactive and had a limited understanding of the world. In the last few months before they died, their lives had become very difficult. Alison's sisters, Lindsay and Julie, got increasingly concerned about how she was coping.

SISTER: Alison's house became a prison for her. She had to lock the doors, and he was obsessive about eating, so she had to lock the cupboards, so he'd get angry about this, because as all children would, they see what they want ...

SISTER: Why can't he have it?

SISTER: He'd see people playing outside – why can't I? You know. So there was always that friction between the two of them.

SPILLER: Alison was a carrier of Fragile X, a condition which can be linked to depression. She had a local social worker, who provided some support. But after a breakdown three years ago, the family became worried Alison was not getting enough help with her disabled son. Alison's sister Julie rang social services to alert them to the pressures her sister was under.

SISTER: I had a notebook and I looked up every department, everybody around the local area, rang them up, told them what had happened, this has happened before, now we'd like to see the corner turning.

SPILLER: Can you remember what sorts of things you were saying to them about your concerns about Alison and the support that she might need?

SISTER: Well, I'd outlined the fact that she had just had another breakdown in hospital, that she was living on her own, that she had a child with special needs and that we'd like to see more things in place for Alison. We needed to know that people were aware and that they were going to do something about it.

SPILLER: Families caring for children with disabilities can be entitled to breaks – time away from looking after children who may have many demands. Respite can come in different forms. Some children may have overnight stays at a residential centre. Some might spend time with another family. And social services can fund or provide carers to help at home or take children out. Stockport Social Services arranged for a local family to look after Ryan for a few hours. But this support broke down.

SISTER: Unfortunately the gentleman got poorly and then instead of then thinking, let's start again, it just stopped. So a great idea, it was really starting to work.

SISTER 2: All that benefit that he was getting socially and emotionally - and Alison - was just stopped dead, nothing more.

SPILLER: Alison was put on a waiting list for another family to provide respite help. And whilst she waited, she was supposed to be getting carers to come and take Ryan out for a few hours, to give her a break. But there were problems with this too.

SISTER: There were not enough care workers to take him out, so they would owe the hours, the hours would build up and she had lots of hours owing to her. And also we had a worry sometimes that it wasn't always appropriate to her when the hours were given.

SISTER 2: She had to meet what they gave her rather than the support services meeting the needs of the family. We were concerned because obviously it was just barely scraping the surface. This doesn't happen without a reason. A person doesn't reach this point in their life just as a, oh, I'll just suddenly do this today or whatever. If there have been things that weren't in place, that weren't followed up and weren't actioned, those are mistakes to be learned from. I think it's extraordinary that somebody who had all these issues didn't get more recognition or help.

**SPILLER:** Alison and Ryan were last seen on April 11<sup>th</sup>. The next day mother and son were captured on CCTV footage on the Humber Bridge. The tragedy became national news. For Alison's sisters though, still grieving, there are many questions left unanswered. Should Alison have got more support? Could Social Services have done more? We wanted to interview Stockport Social Services about Alison's case. They said they couldn't take part in this programme because they were conducting a review, along with other agencies, into the support Alison was offered. They did confirm that Alison was on a waiting list for a family to provide respite care, and that there were problems of staffing when it came to carers looking after Ryan. In a statement they told File on 4 that councils throughout Britain were facing significant pressures on funding.

**READER IN STUDIO:** In many cases it is support to families and preventative services that are facing the biggest pressures. This creates problems for disabled children and their families, as services need to be flexible.

**SPILLER:** Research has shown that parents of disabled children are twice as likely as the rest of the population to be in poor health. If they don't get a break, they are far more likely to suffer from mental health problems. And for Jo Williams at the charity MENCAP, stories like Alison Davies's underline the importance of providing support for parents before they reach crisis point.

**WILLIAMS:** For these families, often struggling on and doing a very good job, we believe that, as a matter of right, they should have some support when they need it. The consequences of not giving support can be very very serious. The very extreme cases, parents become depressed and potentially suicidal and commit suicide, and we know of those tragedies.

**SPILLER:** What do families tell MENCAP about the importance of respite?

**WILLIAMS:** Well, when they come to us, they are often in despair, and they say, 'We are at breaking point, we are at the end of our tether. We just need someone, some services that will enable us to kind of collect ourselves, gather ourselves and go on caring.' They love their children and they don't want to give up, but they need at certain times regular planned breaks.

SPILLER: But a report last month found that over three thousand youngsters were on waiting lists for short break carers. And when it comes to how the system works, the organisation that inspects social services departments in England has highlighted a raft of difficulties. Different local authorities have different criteria for deciding which families have breaks. Different agencies don't talk to each other. The assessments social workers make sometimes don't contain key information and aren't finished on time. Demand for respite services usually far outstrips supply. According to David Behan, the Chief Inspector of the Commission for Social Care Inspection, local authorities might not even know how many families need a respite break.

BEHAN: It's a no-brainer to me that we provide support to parents to help them to provide support to their own children. And therefore what we need to have in place, proper plans so that families are not left without anything, as that is the case at the present time. But there are alternative arrangements that could be brought in.

SPILLER: Are you confident that local authorities know how much unmet need there might be for respite care out there?

BEHAN: I'm not confident that that's exactly where we are at the minute. There's a real difficulty with the figures. The general household survey talks about nationally eleven million adults with disability and about seven hundred and seventy thousand children, and our research shows about twenty seven thousand children using respite care, so we've got quite a gap between the total number of children with disabilities and the provision of respite care services.

SPILLER: Away from concern about the unmet need for breaks, there are now new fears that for some families respite care may disappear altogether. The reason is money. Three months ago, a report from the Association of Directors of Social Services revealed what they claim is a black hole of £1.76 billion in budgets for social care. They said that, amongst the pressures on finances, were the increased needs of carers and medical advances, which mean children and adults with severe disabilities are living longer. For families in some parts of the country, all this is leading to a growing sense of crisis. Deep anxiety about the future of the respite care they say they desperately need.

## ACTUALITY IN PRESTON

SPILLER: Preston in Lancashire, on a chilly summer night, and families are gathering at the County Hall because they're about to confront local politicians.

WOMAN: Well, ever since the letter dropped through the letterbox on the 17<sup>th</sup> February, it's been all day every day, fielding calls from anxious parents, finding out what's going on, because there's been an utter dearth of information.

MAN: I'm very well aware that what we are dealing with are hard-nosed politicians, who really have forgotten that the people who put them there in the first place are the constituents.

SPILLER: All these families care for children with severe disabilities. They get a break when their children go to a local home for the night, a place called Maplewood. But the county council says it has to make cuts. And closing Maplewood would save them £465,000. Inside, a stream of parents tell local politicians what losing Maplewood would mean to them.

## ACTUALITY AT MEETING

WOMAN: I personally have suffered coping with my child for fourteen years on my own, a nervous breakdown. Do you know what I mean? And it's really hard, there's nobody there for you, to give you that respite, because you can regenerate your batteries even with one overnight.

WOMAN 2: This is my daughter Sue and this is my granddaughter Rachel, and Rachel goes to Maplewood. And we have tried and tried for eleven years, and look, my daughter's crying now. We need Maplewood desperately.

MAN: Maplewood is a lifeline, because it's stopped my wife's depression getting worse than it already is. Without that break, I'm sure our family would have been destroyed.



SPILLER: One of the parents at the meeting was Angela Murphy, whose 15 year old son Connor is autistic.

#### ACTUALITY AT ANGELA'S HOME

ANGELA: Connor, will you sit down please?

SPILLER: At her home, Angela showed us a video she's made, to try and convince the authorities why Maplewood - and an overnight break - is so important to her.

#### EXTRACT FROM VIDEO

ANGELA: Go upstairs quietly.

CONNOR: [Shouts]

ANGELA: Quietly!

Oh, that's Connor still up at 2.30 in the morning. I've asked him to go quietly, but he just runs up the stairs shrieking. This happens about three or four times a week. I'm tired, just tired, and when you couple it with the repetitive questioning and the support that he needs, you know, you do get very snappy. He's fifteen, but he needs the supervision and the help of a toddler.

SPILLER: There are suggestions that if Maplewood closes, the council may offer other kinds of respite support. But all the Maplewood parents have signed a letter saying they need the kind of break the centre provides. They believe that without this service, families may fall apart. That in turn might mean their children ending up in residential care - a far more expensive option, they claim, than keeping Maplewood open.

ANGELA: This isn't the expensive option, you know? It helps to keep the child at home, being cared for within their own family. And if you don't get that break, then it may be that you will have to seek a full-time residential placement, which is expensive. It would only take that to happen to three of the families to wipe out the cost savings that they're hoping to make from Maplewood.

SPILLER: Lancashire County Council say they have to make savings because of pressures on their social care budget, more people using their services and a government cap on council tax. They're currently consulting on the proposals to shut Maplewood. Council documents, seen by File on 4, spell out what the closure of Maplewood might mean. The papers suggest there would be less respite provision available per child in other places. The County Council would have to 'review their admission arrangements' in other centres. They'd also have to provide more help from 'Link' families, - families prepared to take children in their own homes to give their parents a respite break. The Leader of Lancashire County Council is Hazel Harding. You heard from families at the meeting that this could be an entirely false economy, that if three families reached breaking point and had to go into residential care, it might wipe out the savings you make from closing Maplewood. So if you do close it, given that argument, you'd be banking – quite literally – on those families not reaching crisis point, wouldn't you?

HARDING: Well, I think we're going down a 'what if' and 'maybe' route there, and we haven't got to that stage.

SPILLER: But families want to know, don't they?

HARDING: Well families do, and I have huge sympathy with the families. I understand the pressures and I have reassured the families that this is a true consultation, that we are listening to them.

SPILLER: How viable are the alternatives though? I understand there are only about eighty-eight Link families in Lancashire, for example, and if Maplewood closes, you're talking about adding another thirty-seven families who want to use the service. So will those families get respite or not? I mean, it's a very very uncertain time, this, isn't it?

HARDING: It's an uncertain time, because we've not taken a decision. We have a very good record. The reason these families are so concerned is because Lancashire County Council has actually dealt with them properly in the past. We've provided over and above the services that some other authorities provide.

SPILLER: The council's own documents analysing the effects of the closure say that the closure of Maplewood will mean less respite provision available per child throughout other establishments and that you'll need to review admission arrangements.

HARDING: Well it would mean that we would look at each individual case, but we haven't got to that stage yet, obviously. That would be something that would be considered if a decision was taken to close Maplewood.

SPILLER: But there's now evidence that pressures on budgets mean local authorities up and down the country are looking at how they might limit the number of families getting respite services. Councils use what are called eligibility criteria to decide which parents might get services like respite breaks. But John Dixon, of the Association of Directors of Social Services, says research his organisation has carried out, suggests that 80% of local authorities are now considering changing this eligibility criteria, when it comes to people with learning and physical disabilities.

DIXON: We're required to set our eligibility criteria in four bands, ranging from a low band up to most critical care. And last year, just under half of local authorities said that they would be able to help people in the second lowest band, which is the moderate band, but this year it's gone to under a third. And that's because people have been having to tighten their belts and give care to fewer and fewer people who are in greater and greater need. And this is a worry to us, because it's also contrary to the national policy direction, and indeed in most areas local policy direction, where we're trying to provide more preventive care to stop people from getting into desperate situations.

SPILLER: In Northamptonshire, the local authority are already looking at proposals to change their eligibility criteria for services they provide to adults with learning disabilities. And here too, the council are considering closing respite homes.

#### ACTUALITY AT CRANWELL

SPILLER: Do you want to tell us where we are?

GIRL: We're in the bedsit at the moment.

SPILLER: This is where you cook, isn't it? This is your kitchen.

GIRL: Yes, yes.

SPILLER: You've got a lovely view out there ...  
This is Cranwell, a respite centre in Northamptonshire. The home provides breaks for adults with learning difficulties. Closing it would save an estimated £250,000.  
Daniel Pennet, Irene Branston and Nicky Brooking come here for a few days away from their families. They're distraught at the thought Cranwell might shut.

GIRL: It's like being at your own home as well, because it's so relaxing and everything.

BOY: I'm very shocked that they'd close this place down. I mean, I've been coming – how many years? – six years I've been coming.

WOMAN: I think it's going to upset everybody if Cranwell closes down. We are angry, we are very angry.

BOY: We are very angry.

WOMAN: It's not fair.

SPILLER: Research has shown that services for disabled children can fall away as they reach adulthood. This means respite breaks for families become even more important. Radio 1 DJ Jo Whiley, has a sister, Frances with a rare genetic condition. Frances's behaviour can be challenging and she has no sense of danger. She's 37 now, and looked after by Jo's elderly parents. Frances goes to another respite centre in Northampton, called Quarry House. It's also facing closure.

WHILEY: The families' reaction when they heard that Quarry House was closing was just kind of desperation really, because it seems like every outlet, every place for someone like Frances to go to has just been closed down. It's just like, 'Oh God, not another one.' Where do you go to? It's just, you know, your choices are so limited. It's ridiculous. It, you know, it just really really makes me despair. I know that cuts have to be made, I know that, you know, they have to find money from one place for another, but it always seems to be people with special needs, disadvantaged people or the elderly, and it's just time and time again. It's just a pattern I've seen throughout Frances's entire life. And it's got harder, it's got much much harder as she's got older.

SPILLER: The council say that cuts have to be made. They want to keep council tax down, they have to make choices. Are you sympathetic to that position? Can you see their argument in all of this?

WHILEY: I can hear their argument, but I don't sympathise, because I can see the hardship that a lot of people are existing under, and I just see the people it's affecting, and I just think it's a desperate situation.

SPILLER: Families in Northamptonshire are now going to be reassessed to determine their needs.

ACTUALITY OF NICOLA AND MARION.

MARION: Why do you like going to Cranwell? Because you're with all your friends your age, aren't you, rather than being with Mummy and Daddy? Yes? Yes?

**SPILLER:** Marion's daughter, Nicola, has a genetic condition which means that at 27, she has a mental age of 3, can't read or write, and has medical problems.

**MARION:** They're actually trying to say, well this person needs respite, that person doesn't, but they haven't changed, they haven't physically changed, they haven't mentally changed, so how they can turn round and say, 'Well, Nicola's allowed it,' or 'Nicola isn't allowed it,' they can't. I don't know. I don't even know what they're trying to do, to be honest with you. It's making life very very difficult, you know, worrying about it.

**SPILLER:** We wanted to interview the Leader of Northamptonshire council. He declined to take part in this programme. In a statement the council told us:

**READER IN STUDIO:** Services we provide to adults with physical and learning disabilities are under review and we are continuing to consult on these matters. This includes reviewing our eligibility criteria to make sure that those who are most vulnerable get the help they need.

**SPILLER:** Earlier this year, the county council faced a legal challenge from parents, who took them to court to attempt to stop the proposals for cuts in services. Local campaigner and solicitor, Yvonne Hossacks, represented the families. For her, changing eligibility criteria is not about making sure the most vulnerable get help, but taking away vital support from parents in need.

**HOSKINS:** The council say, said in their budget that they intend to concentrate their services on the most needy 10%. As an old campaigner, I know that what that actually means is that they're going to take them away from the other 90%.

**SPILLER:** They might not. I mean, that's ...

**HOSKINS:** Well you say that, but actually this council is consulting now and raising its eligibility criteria so that it only provides for people who have critical or highly substantial needs.

SPILLER: But if money is tight, surely that's fair enough. It's a transparent way of doing it, isn't it? You've got to have priorities, haven't you?

HOSKINS: You've got to have priorities and why shouldn't the priority be to give the money to the people who need it, and not to the people who don't? It's very depressing, very stressful, they feel it's a done deal, that if the Archangel Gabriel fluttered down to talk to the council, actually it would make no difference.

SPILLER: The new Minister for Care Services, Ivan Lewis, says the government have made a huge investment in this area, and they can't be blamed for local spending decisions.

LEWIS: People rightly complain about central dictats controlled from offices in Westminster and Whitehall, and then when we say that we delegate and we devolve down to local communities, to local authorities, to health services to make decisions about meeting local need, they then call for almost the nationalisation of these decisions. You can't have it both ways.

SPILLER: Are you going to give them more resources then? And we're talking about a budget shortfall of £1.76 billion, aren't we?

LEWIS: No, no, these figures are just, where do these figures come from?

SPILLER: The Association of Directors of Social Services. They talked about a £1.76 billion shortfall in social services. Are you saying that figure's wrong?

LEWIS: Well, I don't have any independent verification of the figure. I'm not going to get into a spat with the Association of Directors of Social Services, but I don't accept that that figure at the moment is one that I'm familiar with, no.

**SPILLER:** But with councils looking at changing their guidelines about who's entitled to help, there's a new fear - that the burden of paying for respite will fall increasingly on parents. And some families are now claiming that councils are means-testing parents by the back door when it comes to respite care for their disabled children. Chloe Russell is 15, with profound disabilities. She has cerebral palsy and very restricted mobility. She can't talk, has hearing problems, epilepsy and is incontinent. When she is home from her residential school, Bob Russell says he and his wife, both in their late fifties, can find caring for her a huge strain.

**RUSSELL:** To change Chloe's pad takes at least half an hour, because you have to hoist her out and onto the bed, you have to fight with her because she doesn't like it, she thinks she's going to bed, we think she thinks she's going to bed. She screams and shouts, we have to change her. She's heavy work, a person that has a rigid back, which Chloe's got since her operation, to lift her and roll her, to change her, it's hard work. Chloe has, is doubly incontinent, she has a lot of trouble going to the loo, so she's constantly dirty, she constantly needs cleaning up, so she has to be cleaned up several times or more than several times during the day to keep her clean.

**SPILLER:** In the past, Oxfordshire County Council paid for Chloe to go to a centre called the Chilterns. But Chloe's care was re-assessed and the local social services department decided they'd no longer pay for respite breaks there. The Russells have fought a long-running battle to convince them that they need the help the Chilterns centre provides. Bob says it's put the family under great stress.

**RUSSELL:** My wife, well on Easter Sunday evening, got seriously drunk and we both had a stressful day and she started talking about suicide and I didn't know how to deal with it, so I rang the doctor. I mean, I think it's a horrendous indictment of the system which seems to, seems to have abandoned us. It's driven us to the edge. I've been, all the tablets that we might have in the house I've been carrying around in my bag for at least a month, because I've realised how distressed she was. I just worry about her. I mean, she's, yes, I worry about her.



SPILLER: The County Council closed the Chilterns centre in 2003. Since then it's been re-opened and run as a Charitable Trust. Bob now pays for Chloe to go there, because he says this respite is vital when it comes to keeping the family from breaking down. He thinks Social Services should help fund some of this support. A few weeks ago, he discovered they'd made a decision about Chloe's care, based on taking the family's income into account.

RUSSELL: At the meeting we had on May 3<sup>rd</sup>, I asked them how they made the decisions, and they said, 'Well, the decision is based on the fact that you are in work and your wife works part time, therefore we believe you can afford to pay for Chilterns.' So I said to them, 'You mean it's means-tested?' and they said, 'Yes.' Now it's not means-testing as you or I would understand it, because I think means-testing also has to consider outcome. I mean, irrespective of how much your mortgage is, you know, I'm paying for a vehicle to transport Chloe, which cost us £25K, you know. That's quite a sizeable commitment out of my salary, and Chloe is welcome to this vehicle because she needs something safe to move her in, etc, but it's not the way you do means testing.

SPILLER: Some would say if you can pay for respite care, budgets are tight, people like you should. What do you think of that argument?

RUSSELL: We willingly pay for Chloe at the moment. I don't think we should be paying for it all. I really don't think we should be paying for it all, because I think Chloe has an entitlement in law to respite care.

SPILLER: The local authority maintain that Chilterns is a play and leisure centre and so, they say, Bob's paying for his daughter to be on a play scheme. And Sarah Ainsworth at Oxfordshire Social Services, says that whilst the local authority do not means-test for respite, they do means-test families when it comes to play and leisure services.

AINSWORTH: When we do the assessment, we look at people's economic circumstances in broad terms. If they are in employment and they are not raising any particular concerns about their financial background, then we make the assumption that they can afford to pay, as families would if they have other children who want to access holiday play schemes.

SPILLER: You don't make it very clear, though, do you, in your service allocation guidelines, that you are, in fact, making these assumptions about people's income, that you are effectively means-testing them?

AINSWORTH: What we say - and I will quote - a family's current level of support from families, friends and other services will be taken into account when deciding the size of a care package.

SPILLER: But in terms of respite care, you means-test people for respite care, do you?

AINSWORTH: Not for overnight residential respite or for overnight family-based respite or indeed for what we call relief to care services, which is the sitting service in children's homes. It's only for weekend and after school and holiday play schemes, which are fun for children and also, of course, give families a break.

SPILLER: As you know, we've talked to Bob Russell, and certainly his income was taken into account by a panel, wasn't it, in terms of respite care for his daughter?

AINSWORTH: What he accesses was day care at Chilterns funded by them to maintain peer group contact. That is a play and leisure facility and that is what he funds himself, and we feel that it is appropriate for them to purchase a level of respite themselves.

SPILLER: So is the break Chloe gets respite for her family or a play scheme? A spokesman at the Chilterns Centre told File on 4 that they do not provide play and leisure facilities. They provide respite care.

#### EXTRACT FROM NEWS

NEWSREADER: The Chief Executive of the NHS in England is retiring early amid claims that the financial crisis in the health service is far worse than forecast.

NEWSREADER 2: Tony Blair has been meeting health service managers to discuss the financial problems facing some NHS Trusts. A Chief Executive who ...

SPILLER: On top of concerns about pressures on social services' budgets, there is now real anxiety that the funding crisis in the NHS will put further strain on local authorities. And what that might mean are more cuts in services. In many areas, health and social services have been pooling budgets and funding services together. In some parts of the country, services like respite care could go if the NHS pulls money out of these joint programmes. File on 4 has seen new evidence about the impact of this. An unpublished report reveals that fifteen local authorities are already experiencing significant problems, because the NHS has withdrawn money. The total shortfall in these authorities from the NHS pulling out funding is calculated at £6.5 million. And the draft report from the Local Government Association says some local authorities are experiencing 'real difficulties which need to be resolved'. John Dixon's organisation, the Association of Directors of Social Services, has been monitoring the effects of the NHS deficit across the country.

DIXON: There are couple of areas in the country where it is having a huge impact, because we're talking about multi-million pound transfers affecting local authorities. It means that the NHS are not able to come alongside us in the new developments that we need to meet the needs of these sort of people.

SPILLER: And are there examples of respite care being cut back because of the effects of the NHS deficit?

DIXON: That's the sort of thing that can be, where you have specialised and residential respite care, it can be cut back and that really does have an effect, because where people, particularly where carers are not getting the care they need, then it may be that they simply aren't going to be able to carry on caring, and the local authority or the NHS are going to be having to pick up the consequences.

SPILLER: This April, Dr Ray Jones left his post as Director of Social Services at Wiltshire County Council after the NHS withdrew £3 million from a joint fund with the local authority. He's now chair of the British Association of Social Workers. He says that if the NHS fails to provide care services, families may have to pay for them themselves.

JONES: I think it's significant in two ways. Firstly, the size of the deficit nationally, which I think is being quoted as in excess of £700 million, clearly is a big deficit. And probably about 20% of that, I think, has a knock-on effect when the NHS makes cuts directly onto social care and then onto disabled and older people. If people move from a service which is exclusively funded by the NHS to a service funded by the local authority, they move from a free NHS service – healthcare in this country is free – to a means-tested social care service, where they will be assessed in terms of their ability to contribute towards the cost of the assistance that they're receiving. And if local authorities take on that responsibility and charge people for it within means-tested social care, are they effectively, the disabled person in their family, being charged for what should be a free NHS service?

SPILLER: And what do you make of that?

JONES: Well, there's a real tension there and that's going to have to be decided somewhere along the line - probably by the courts.

SPILLER: Five years ago, the Government set out a vision for supporting people with learning disabilities. In a key White Paper, called Valuing People, they talked about supporting carers, providing services to help them maintain their health and well-being. Dr Jones says that five years on, the Government's vision of how to help people with disabilities achieve a better quality of life is increasingly at odds with reality.

JONES: I think it's a very difficult time, and I think it's a very difficult time because – and the Government itself has a vision for social care and how it would like the life experience for disabled people and their families to be, which is very positive, it's a very positive vision about people having more choice and control within their lives and a better quality of life and more opportunity. But it's very difficult



